

**SURVEY OF ADULTS RECEIVING
DEVELOPMENTAL SERVICES
VERMONT
SUMMER 2004**

Consumer Survey Project

Report Prepared June 2005

For

The Division of Disability and Aging Services
Vermont Department of Disabilities, Aging and Independent Living
103 South Main Street
Waterbury, VT 05671-1601

This Report describes findings from a survey of adults receiving developmental services across Vermont. The survey was conducted by members of the Vermont Consumer Survey Project in the summer of 2004. The coordinating members of the Vermont Consumer Survey Project are:

June Bascom, M.Ed. - Project Director
Rosemary Drabing, M.S.W. - Survey administration and data entry.
Janet Bramley, Ph.D. - Data analysis and report preparation.

For questions about this report or requests for further copies, please contact:

June Bascom
The Division of Disability and Aging Services
Vermont Department of Disabilities, Aging and Independent Living
103 South Main Street
Waterbury, VT 05671-1601

FOREWORD

We at the Division of Disability and Aging Services are committed to the continual improvement of the developmental services we provide and we believe that a critical part of that commitment is listening to the people we serve. Our first statewide in-depth consumer surveys took place in 1995 using a questionnaire originally developed by Drs Susan Culbert and Sara Burchard from the Psychology Department at the University of Vermont. Over time, this questionnaire has been revised and enhanced in consultation with our consumer advocates. The information from the surveys has not only helped us to gain a clearer picture of who we serve, but to better understand what people feel is important to their quality of life and how we can better support them.

This report contains findings from the first year in the third 3-year cycle of surveys. Those of you who have been reading previous consumer reports will find a number of significant changes in the way in which the information is presented. The report now includes more demographic information, has added findings on Self-Determination and Rights, and perhaps the most significant change is comparison information from the previous survey so that you can see how opinion has changed over time.

We hope you find this both informative and helpful as you develop your future systems of support.

Theresa A. Wood
Deputy Commissioner
Department of Disabilities, Aging and Independent Living

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SECTION 1

OVERVIEW

INTRODUCTION

The summer of 2004 marked the start of the third 3-year cycle of satisfaction surveys of adults with developmental disabilities served by the State of Vermont Division of Disability and Aging Services. The same six agencies were surveyed as in 2001: Community Associates (CA), Champlain Vocational Services (CVS), Howard Center for Human Services (HCHS), Northeast Kingdom Human Services (NKHS), Specialized Community Care (SCC), and United Counseling Service (UCS).

In its continuing efforts to provide quality services, the Division has extended the scope of the original demographic and satisfaction surveys used in 1995 to better understand the needs and wishes of people served by developmental service agencies. For example, revisions to the last cycle of surveys started in 2001 included expanded demographic information and new survey questions on self-determination based on input from self-advocates. Work on the survey for this cycle starting in 2004 has included further alignment with questions on the National Core Indicators (NCI) survey to enable comparisons with other states nationally on a greater range of questions.

Substantial changes have also been made to the presentation format for the 2004-2006 survey reports: the reports now include more demographic information about the participants, results are presented as percentages, and there are comparisons between this year's findings and those of the previous surveys in 2001. The reports now consist of four major Sections:

- **Overview:** The survey process consists of two parts: a demographics survey and the satisfaction survey itself. This Section is for readers who would like a brief stand-alone summary of survey findings for the summer of 2004. It gives a basic description of the interviews, a brief profile of the respondents, and how they rated their satisfaction in a range of life domains. For comparison purposes, the information about people served by the same six agencies in 2001 is also included.
- **Consumer Survey 2004 - What People Had To Say.** This Section is for readers who would like more detail on how people responded to individual questions on the survey. It first gives comparison information from the 2001 and 2004 surveys on selected questions within the life domains. Further detail on domain scores is then given. The final part of this Section includes the full set of responses to the 2004 survey questions.
- **Participant Profile 2004 - Who Participated.** This Section reports the findings from the demographics survey so that each agency can have a clear picture of the population of adults they serve. Each reporting category includes numbers for those interviewed and those not interviewed.
- **Methodology - How This Survey Is Conducted.** This Section describes the procedures for collecting survey information and how that information is analyzed for reporting purposes.

SUMMARY OF FINDINGS: STATE OF VERMONT 2004

The selection of adults to participate in the consumer surveys is designed to be representative both within each agency and to be representative of the statewide population of consumers in each year. In the summer of 2004, the independently contracted survey team visited the same six agencies as were surveyed in 2001. 100% of those who are able to respond to the survey at smaller agencies (specialized service agencies) and 50% from the larger designated service agencies were invited to be interviewed. For Howard Center for Human Services a sample of 33% of the current caseload is selected for each year of the 3-year survey cycle. Interviews took an average of 31 minutes to complete in 2004 and 32 minutes in 2001. As can be seen from Table 1.1, the response rate for 2001 (in parentheses) was a little higher than the statewide rate for 2004.

Table 1.1 – Participants and Types of Interviews Conducted (N=373)

	CA	HCHS	NKHS	SCC	UCS	CVS	Total 2004 (2001)
Interviewed							
Full interview	56%	35%	51%	6%	45%	42%	42% (49%)
Picture only	4%	6%	9%	0%	9%	21%	8% (13%)
Total Interviewed	60%	41%	60%	6%	54%	63%	50% (62%)
Not Interviewed							
Agency decision	13%	19%	9%	26%	5%	8%	13% (24%)
Guardian's decision	2%	1%	0%	0%	0%	0%	1% (0.5%)
Unable to complete	2%	0%	4%	3%	7%	5%	3% (1%)
No Show/Person's choice	17%	29%	13%	26%	29%	11%	20% (8%)
Person out of town	0%	0%	4%	6%	0%	3%	2% (1%)
Person incapacitated	2%	8%	4%	23%	2%	5%	6% (0.5%)
Scheduling oversight	2%	0%	3%	0%	0%	0%	1% (1%)
Other	2%	2%	5%	10%	3%	5%	4% (2%)
Total not Interviewed	40%	59%	40%	94%	46%	37%	50% (38%)
Total Participants	52	86	110	31	56	38	373 (410)

In order to be able to draw valid comparisons between findings at the state and local level it is important that the profile of those giving their opinions about life satisfaction is broadly the same. Table 1.2 compares some of the main demographic characteristics of the people surveyed in 2001 and 2004. No noticeable differences were found between the 2001 and 2004 interview groups.

Table 1.2 – Brief Profile of Consumers Interviewed

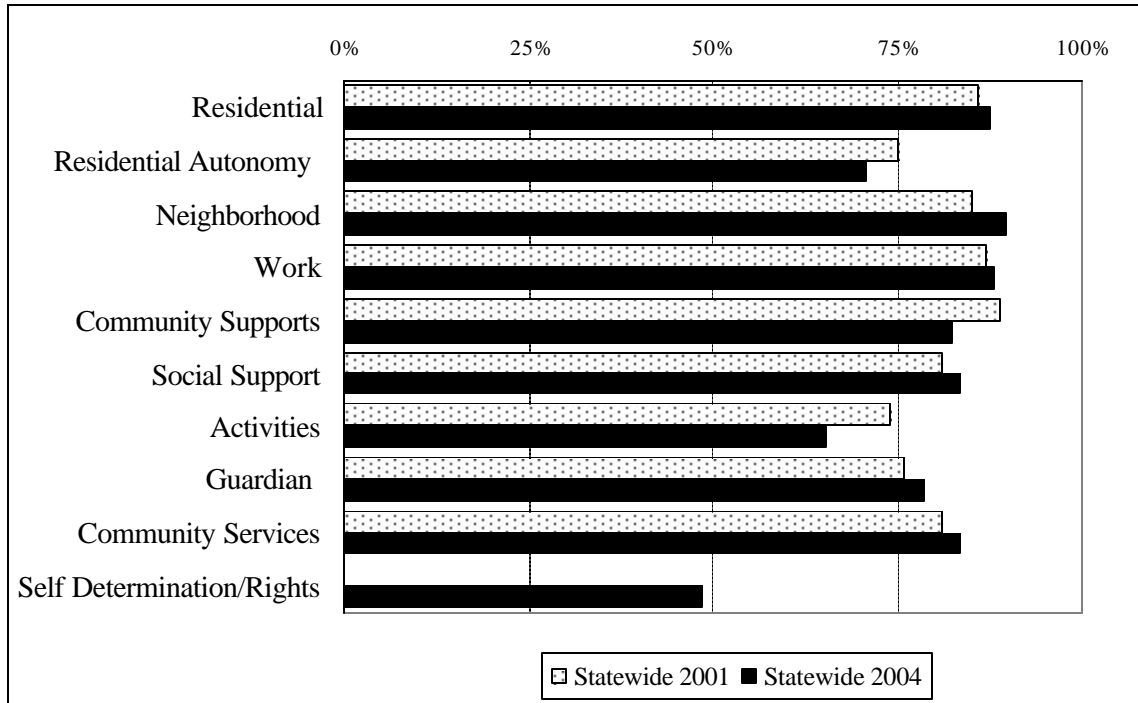
	Statewide 2001 (N=253)	Statewide 2004 (N=188)
Age		
Average Age	40	41
Minimum Age	18	19
Maximum Age	87	83
Gender		
Male	55%	60%
Female	45%	40%
Developmental Disability Label		
Mild MR	74%	72%
Moderate MR	18%	21%
Severe MR	3%	4%
Unknown	5%	3%
Living Situation		
Provider Home	32%	35%
Family Home	29%	27%
Person's Own Home	23%	28%
Group Living	8%	8%
Other	8%	3%
Services Received		
Service Coordination	91%	92%
Residential Supports*	40%	44%
Community supports	51%	53%
Employment - individual supported	51%	52%
Family supports - Respite/FFF	44%	42%

* In Provider Home, Group Living, or Staffed Living

The analysis of responses to the consumer survey involved grouping responses into scales reflecting a series of life satisfaction domains (Table 1.3). The scales for the 2004 survey are the same as in 2001 with the following exceptions: the Health scale has been dropped and a new Self-determination/Rights scale has been added. Since the Self-determination/Rights scale is based on new or revised questions, a direct comparison of satisfaction in this domain was not possible. It should be noted that community support was formerly called day program.

The 2004 results indicate a general trend toward slightly increased satisfaction across most domains except for Residential Autonomy, Community Supports and Activities where satisfaction levels were lower. Significantly decreased satisfaction in Activities was noted at both state and local levels. In general, more people expressed a wish to take part in more community and social activities than they did in 2001. This may, in fact, be a positive result in that it indicates a desire to have more community and social interaction. Satisfaction in several of the other life domains showed some increases but none at a significant level.

Table 1.3 - Comparative Satisfaction by Domain



Domain	Statewide 2001 (N=253)	Statewide 2004 (N=188)
Residential	86%	88%
Residential Autonomy	75%	71%
Neighborhood	85%	90%
Work	87%	88%
Community Supports	89%	83%
Social Support	81%	84%
Activities	74%	65%
Guardian	76%	79%
Community Services	81%	84%
Self Determination/Rights	-	49%

SECTION 2

CONSUMER SURVEY 2004

WHAT PEOPLE HAD TO SAY

This Section focuses on how people responded to the consumer survey in 2004. The selected highlights also include comparative statewide responses from the survey in 2001. A brief profile of the adults who were interviewed is given in Section 1 and full demographic information on all survey participants for 2004 is available in Section 4.

The method used for collecting survey data is designed to obtain feedback that is broadly representative of consumer opinion statewide each year. In each of the years since 2001, this has been done by interviewing a random selection of consumers from a sampling of agencies based on agency size and regional representation. Consumers from the same six agencies participated in the survey in 2001 and 2004.

CONSUMER RESPONSE HIGHLIGHTS

Each of the tables below highlights responses that illustrate trends in a given satisfaction domain. For comparison purposes, the tables include the responses the responses of all people interviewed statewide in both 2001 and 2004. The columns show the percentage of respondents whose response agreed with each statement. For full details of how the participants responded to the full set of survey questions in 2004, see page 14.

Table 2.1 – Residential

	Statewide 2001	Statewide 2004
• I like where I live	82%	91%
• I cannot think of anywhere better to live	71%	62%
• I'm happy about how I spend my free time	81%	78%
• I'm happy with the chores I do	78%	77%
• I feel safe at home	86%	97%
• I can get to places (like Drs, Agency, shops)	81%	76%

Table 2.2 – Residential Autonomy

	Statewide 2001	Statewide 2004
• I had a say in where I live	49%	62%
• I choose what I wear	90%	84%
• I can change the rules at my house	60%	56%
• I can invite friends/family over whenever	82%	89%
• I have privacy when friends/family visit	73%	74%
• I have a say how to spend my money	82%	98%
• I can stay home if I want to	61%	62%

Table 2.3 – Neighbors/neighborhood

	Statewide 2001	Statewide 2004
• Neighbors are friendly	86%	92%
• I like the neighborhood	80%	87%
• I feel safe in the neighborhood	84%	94%

Table 2.4 – Work

	Statewide 2001	Statewide 2004
• I chose my job by myself	25%	43%
• I like my job	88%	97%
• I work enough hours at my job	64%	68%
• The people I work with respect me	87%	88%
• I chose my job coach by myself	20%	50%
• There's nothing I'd rather do during the day	81%	67%

Table 2.5a – Community Supports (Individual)

	Statewide 2001	Statewide 2004
• I like my (individual) community activities	95%	96%
• I have enough (individual) community activities	63%	60%
• I like the people I spend time with	87%	87%
• I chose my support person by myself	25%	33%
• There's nothing I'd rather do during the day	77%	67%

Table 2.5b – Community Supports (Group)

	Statewide 2001	Statewide 2004
• I like my(group) community activities	93%	100%
• I have enough (group) community activities	69%	67%
• I like the people I spend time with	97%	80%
• I chose my support person by myself	33%	50%
• There's nothing I'd rather do during the day	76%	84%

Table 2.6 - Friends/Social Supports

	Statewide 2001	Statewide 2004
• I have plenty of friends	74%	73%
• I can see my friends when I want	85%	88%
• I have friends I like to talk/be with (not staff or family)	-	74%
• I'm not often lonely	56%	60%
• I see my family when I want	71%	84%

Table 2.7 – Activities*

	Statewide 2001	Statewide 2004
• I shop as much as I want	79%	62%
• I exercise/play sport as much as I want	77%	56%
• I eat out as much as I want	72%	67%
• I go to church/synagogue as much as I want	74%	61%

* Activities satisfaction includes those who take part in the activity as much as they want and those who choose not to do so.

Table 2.8 - Guardianship

	Statewide 2001	Statewide 2004
• I'm happy about my guardian	80%	82%
• I chose my guardian myself	46%	52%
• I see my guardian whenever I want to	82%	90%
• My guardian lets me make my own decisions	67%	69%

Table 2.9 - Community Services

	Statewide 2001	Statewide 2004
• I'm happy with my service agency	82%	83%
• I chose my case manager myself	22%	31%
• I'm happy with my case manager	89%	83%
• I can see my case manager whenever I want	71%	85%
• People listen to me at ISA meetings	90%	94%

Table 2.10 - Self Determination/Rights

	Statewide 2001	Statewide 2004
• I have attended a self advocacy meeting	33%	39%
• I get to learn new things/skills	41%	80%
• I have enough control over my life	82%	82%
• I make all the choices I want	21%	64%

DOMAIN SATISFACTION

In order to obtain a better overall picture of what people who receive our services think, the responses to survey questions are grouped to reflect a range of life satisfaction domains. The questions used to analyze each domain are listed in Section 4.

In the first instance, domain satisfaction was examined across everyone who was interviewed in 2004 and 2001. Table 2.11 shows that, for the most part, people in 2004 responded in similar fashion to people from participating in the 2001 survey. Satisfaction was generally a little higher in 2004 across the domains except for a slight decrease in the Residential Autonomy and Community Supports domains and a substantial drop in satisfaction with Activities. This may, in fact, be a positive result in that it indicates an understanding of choices in the home and a desire to have more community and social interaction.

Table 2.11 - Comparative Domain Satisfaction

Domain	Statewide 2001 (N=253)	Statewide 2004 (N=188)
Residential	86%	88%
Residential Autonomy	75%	71%
Neighborhood	85%	90%
Work	87%	88%
Community Supports	89%	83%
Social Support	81%	84%
Activities	74%	65%
Guardian	76%	79%
Community Services	81%	84%
Self Determination/Rights	-	49%

When further analyses of domain satisfaction by respondent characteristics were completed, only one significant difference was found. When domain satisfaction was examined by the types of home setting, it was found that people who lived independently rated their Residential Autonomy significantly higher than those who lived in other residential settings (Table 2.12). There was no significant difference between Residential Autonomy ratings given by people living in family homes and those in provider homes. No statistically significant differences were found on the other domains by residential type. Similarly, examination of community support satisfaction by type of support (individual or group) and guardian satisfaction by type of guardian showed no significant differences.

Table 2.12 - Domain Satisfaction by Residential Type - 2004

Domain	Family Home (n=50)	Semi-Independent Living (n=52)	Provider Home (n=66)	All Residential Settings (n=188)
Residential	89%	88%	88%	88%
* Residential Autonomy	69%	84%	62%	71%
Neighborhood	90%	89%	90%	90%
Work	89%	89%	85%	88%
Day Program	83%	87%	82%	83%
Social Support	85%	84%	82%	84%
Activities	61%	74%	63%	65%
Guardian	83%	76%	76%	79%
Community Services	85%	82%	83%	84%
Self Determination/Rights	48%	53%	45%	49%

*People living semi-independently rated Residential Autonomy significantly higher ($p<.05$) than those in other home types

SURVEY RESPONSES, 2004: STATEWIDE (N=188)

The following pages provide details of how people across the six participating agencies responded to individual questions on the Consumer Survey in the summer of 2004. The Vermont Consumer Survey Project is participating in the National Core Indicators (NCI) project. The aim of the project is to establish and validate “core indicators” to serve as benchmarks against which states can examine and evaluate the satisfaction of people receiving developmental services. Questions included in the national project are indicated in the table of results with asterisks (*). The percentages given in the results below are the percentages of those consumers who answered the question.

RESIDENTIAL

*1. Do you like where you live? Who do you live with?

RESPONDENTS	YES	IN-BETWEEN	NO
187	91%	5%	4%

*2. Who chose (picked) the place where you live? (Did somebody help you make this choice?)

RESPONDENTS	SELF	SELF WITH HELP	SOMEONE ELSE
137	19%	43%	38%

3. Can you think of a place you would rather live?

RESPONDENTS	NO	YES, NOT NAMED	YES, NAMED
150	62%	3%	35%

4. Is the food there pretty good or do you not like the food there?

RESPONDENTS	LIKE	IN-BETWEEN	NOT LIKE
150	95%	3%	2%

5. Show me how you feel about the food at your house.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
149	84%	12%	4%

6. Who decides (picks) what you eat?

RESPONDENTS	SELF	SOMEONE ELSE, I LIKE IT	SOMEONE ELSE, I DON'T LIKE IT
147	59%	38%	3%

7. Who decides (picks) what you wear?

RESPONDENTS	SELF	SOMEONE ELSE, I LIKE IT	SOMEONE ELSE, I DON'T LIKE IT
147	84%	15%	1%

*8. Who decides when you do things each day (like when to get up, when to eat dinner, what to watch on TV, when to go to bed?)

RESPONDENTS	SELF	SELF WITH HELP	SOMEONE ELSE
146	73%	19%	8%

9a. Do you like or dislike ____ ? (Average Family/Housemates 1 through 3)

RESPONDENTS	LIKE	IN-BETWEEN	NOT LIKE
80	91%	7%	2%

9b. Do you like or dislike ____ ? (Average Paid Housemates 1 through 3)

RESPONDENTS	LIKE	IN-BETWEEN	NOT LIKE
75	93%	4%	3%

10a. Is ____ nice and polite to you? ? (Average Family/Housemates 1 through 3)

RESPONDENTS	POLITE	SOMETIMES	NOT POLITE
78	94%	6%	0%

*10b. Is ____ nice and polite to you? (Average Paid Housemates 1 through 3)

RESPONDENTS	POLITE	SOMETIMES	NOT POLITE
72	94%	5%	1%

11a. Show me how you feel about ____? (Average Family/Housemates 1 through 3)

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
81	86%	10%	4%

11b. Show me how you feel about ____? (Average Paid Housemates 1 through 3)

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
78	89%	8%	3%

*12. Did you choose (pick) the people you live with?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
52	27%	33%	40%

*13. Did you choose who helps you at home?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
37	43%	25%	32%

*14. Have you had too many different people support you there? Is that a problem?

RESPONDENTS	NO	IN-BETWEEN	YES
37	78%	3%	19%

15. (For persons living semi-independently with no roommate) Do you like living by yourself?

RESPONDENTS	YES	IN-BETWEEN	NO
28	82%	7%	11%

16. Would you like to have someone live with you?

RESPONDENTS	NO	IN-BETWEEN	YES
28	64%	11%	25%

THINGS TO DO:

What do you do for fun when you are at home? (*Not during community or work supports.*)

*17. Who decides how you spend you free time? (Who decides what you do for fun? Who chooses the activities you do?)

RESPONDENTS	SELF	SELF WITH HELP	SOMEONE ELSE
148	70%	20%	10%

*18. Do you have enough to do when you're at home or do you sit around with nothing to do?

RESPONDENTS	ENOUGH	IN-BETWEEN	NOTHING
152	82%	13%	5%

*19. Are you bored when you are at home, or is it fun to be home?

RESPONDENTS	FUN	IN-BETWEEN	BORED
154	64%	27%	9%

20. Show me how you feel about how you spend your free time at home.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
184	78%	18%	4%

JOBS/CHORES:

21. Are you told what jobs to do or do you get to pick the jobs/chores you want to do?

RESPONDENTS	PICK	IN-BETWEEN	TOLD
128	71%	12%	17%

22. Would you like to have more jobs/chores to do?

RESPONDENTS	NO	SOMETIMES	YES
130	77%	3%	20%

23. Show me how you feel about the jobs/chores you do around your house.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
155	77%	16%	7%

RULES:

24. Who makes the rules for living here?

RESPONDENTS	SELF	SOMEONE ELSE
57	23%	77%

25. Are the rules for living there good rules or are they bad rules?

RESPONDENTS	GOOD	IN-BETWEEN	BAD
55	84%	13%	3%

26. What happens if you don't like a rule? Can you change a rule? (like when you have to go to bed etc.)?

RESPONDENTS	CHANGE IT	IN-BETWEEN	CAN'T CHANGE
48	48%	8%	44%

27. Show me what you think about the rules at your house.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
72	71%	17%	12%

28. What if you want to drink a beer or some wine in your house? Is there no drinking allowed there (at home) or can you have a beer or wine there (at home) if you want?

RESPONDENTS	HAVE A DRINK	IN-BETWEEN	NOT ALLOWED
96	70%	2%	28%

29. Can you invite your friends or your family over to your house whenever you want to?

RESPONDENTS	YES	IN-BETWEEN	NO
143	89%	2%	9%

30. Who decides when you can have friends/family over to visit?

RESPONDENTS	SELF	IN-BETWEEN	OTHER
132	56%	10%	34%

PRIVACY:

*31. Can you be alone if you want to? (Do you have privacy?)

RESPONDENTS	YES ENOUGH	WANT MORE TIME ALONE
146	85%	15%

*32. (If people get mail) Does anyone ever open your mail without asking you first?

RESPONDENTS	YES	SOMETIMES	NO
130	10%	2%	88%

*33. Can you use the telephone when you want to?

RESPONDENTS	YES	SOMETIMES	NO
147	91%	1%	8%

34. Can you talk on the phone in private or do other people listen in?

RESPONDENTS	HAVE PRIVACY	SOMETIMES	LISTEN IN
130	88%	4%	8%

*35. (If friends come over to visit?) Can you be alone with them, or does someone have to be with you?

RESPONDENTS	HAVE PRIVACY	SOMETIMES	NOT ALONE
108	74%	6%	20%

36. Has anyone ever talked to you about dating? (Having a boyfriend/girlfriend?)

RESPONDENTS	YES	NO
135	37%	63%

37. Do you need to know more about dating? (Having a boyfriend/girlfriend?)

RESPONDENTS	NO	YES
132	68%	32%

38. Do you have a boyfriend/girlfriend?

RESPONDENTS	YES	NO
129	39%	61%

39. Can you have (boyfriend/girlfriend) over to visit whenever you want?

RESPONDENTS	YES	SOMETIMES	NO
108	74%	7%	19%

40. Can (boyfriend/girlfriend) stay overnight at your house if you want, or is (boyfriend/ girlfriend) not allowed to stay overnight?

RESPONDENTS	YES, ALLOWED	SOMETIMES	NOT ALLOWED
35	54%	6%	40%

41. Can you go to (boyfriend/girlfriend)'s house as much as you want?

RESPONDENTS	YES	SOMETIMES	NOT ALLOWED
45	87%	4%	9%

MONEY:

42. Can you have your own money whenever you want it or do you have to ask someone for your money?

RESPONDENTS	HAVE IT	ASK FOR IT
148	58%	42%

43. Show me how you feel about (self or other) having your money.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
134	80%	10%	10%

*44. Do you choose what to buy with your spending money (Did someone else decide how you spend your money?)

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOOSES
146	65%	33%	2%

45. Do people steal (take) your money?

RESPONDENTS	NO	YES
151	97%	3%

SAFETY:

46. Do people in your house take your things or do they leave your stuff alone?

RESPONDENTS	LEAVE ALONE	SOMETIMES	TAKE
137	96%	0%	4%

*47. Do people let you know before they come to your house?

RESPONDENTS	YES	SOMETIMES	NO
141	88%	6%	6%

*48. Do people let you know before coming into your bedroom?

RESPONDENTS	YES	SOMETIMES	NO
138	82%	5%	13%

*49. Do you feel safe in your home or do you feel afraid (scared) in your home?

RESPONDENTS	SAFE	IN-BETWEEN	AFRAID
154	97%	1%	2%

COMING AND GOING:

50. When people in your house go somewhere, do you have to go or can you stay home alone if you want to?

RESPONDENTS	CAN STAY ALONE	IN-BETWEEN	HAVE TO GO
122	62%	8%	30%

51. Do you have a key to your house?

RESPONDENTS	YES	NO
145	66%	34%

ACCESS/ TRANSPORTATION

*52. When you want to go somewhere, do you have a way to get there?

RESPONDENTS	YES	SOMETIMES	NO
139	91%	6%	3%

53. Are there places that you need that you need to go that you can't get to? (Such as to the doctor, the service agency, to go shopping, to the pharmacy, etc.)

RESPONDENTS	NO	SOMETIMES	YES
142	76%	11%	13%

PETS:

54. Are there any pets at your house?

RESPONDENTS	YES	SOMETIMES	NO
155	71%	0%	29%

55. Do you like having a pet? (Persons with a pet)

RESPONDENTS	YES	IN-BETWEEN	NO
110	95%	0%	5%

56. Do you want to have a pet? (Persons without a pet)

RESPONDENTS	NO	SOMETIMES	YES
44	59%	9%	32%

NEIGHBORHOOD:

57. Are your neighbors/people who live near you friendly toward you?

RESPONDENTS	YES	SOMETIMES	NO
120	92%	5%	3%

58. Are your neighbors/people who live near you mean to you or nice to you?

RESPONDENTS	NICE	IN-BETWEEN	MEAN
121	88%	10%	2%

59. Do you like living in your neighborhood the area where you live or would you like to live in a different neighborhood/area?

RESPONDENTS	LIKE IT	IN-BETWEEN	DIFFERENT PLACE
138	86%	7%	7%

60. Show me how you feel about your neighbors.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
149	79%	15%	6%

*61. Do you feel safe to be out in your neighborhood/the area near your house, or do you feel afraid to be out in your neighborhood/the area near your house?

RESPONDENTS	SAFE	IN-BETWEEN	AFRAID
134	94%	4%	2%

WORK

62. Do you have a job?

RESPONDENTS	YES	NO
150	59%	41%

63. Do you want to have a paid job?

RESPONDENTS	NO	SOMETIMES	YES
59	63%	3%	34%

64. Do you like your job or do you dislike your job?

RESPONDENTS	LIKE	SOMETIMES	DISLIKE
89	97%	3%	0%

*65. Did you choose to work at _____?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
86	43%	48%	9%

*66. Do you like working there?

RESPONDENTS	YES	IN-BETWEEN	NO
88	97%	3%	0%

67. Do you work enough hours or do you want to work more hours?

RESPONDENTS	ENOUGH	IN-BETWEEN	MORE
83	68%	2%	30%

68. Is the work you do important work or not important work?

RESPONDENTS	IMPORTANT	IN-BETWEEN	NOT IMPORTANT
80	96%	1%	3%

69. Do you get paid enough for the work you do?

RESPONDENTS	YES	IN-BETWEEN	NO
86	93%	1%	6%

70. Show me how you feel about the money you make from work.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
100	82%	16%	2%

Do you have a job coach/someone/staff who helps you do your job?

*71. Is _____ nice and polite to you?

RESPONDENTS	NICE	IN-BETWEEN	NOT NICE
52	100%	0%	0%

*72. Did you choose _____ to help you at work?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
53	50%	21%	29%

73. Show me how you feel about the other people (co-workers) you work with.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
96	88%	10%	2%

74. Do the people you work with treat you okay, or do they not respect you?

RESPONDENTS	RESPECT	IN-BETWEEN	NO RESPECT
85	93%	6%	1%

75. Do you have to work all the time or do you get a vacation from work?

RESPONDENTS	VACATION	IN-BETWEEN	ALL THE TIME
84	89%	5%	6%

76. Show me how you feel about work.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
99	85%	14%	1%

77. Have you too many different people support you at work?

RESPONDENTS	NO	IN-BETWEEN	YES
58	83%	3%	14%

78. Is there something else you would rather do during the day?

RESPONDENTS	NO	SOMETIMES	YES
81	67%	5%	28%

79. Do you choose to go to work, or do you have to go?

RESPONDENTS	CHOOSE	SOMETIMES	HAVE TO GO
84	58%	0%	42%

COMMUNITY ACTIVITIES- INDIVIDUAL SUPPORT

80. Do you like your community activities or do you not like them?

RESPONDENTS	LIKE	SOMETIMES	NOT LIKE
72	96%	1%	3%

81. Did you choose (pick) your community activities?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
72	45%	47%	8%

82. Do you like doing those activities?

RESPONDENTS	YES	IN-BETWEEN	NO
82	99%	0%	1%

83. Do you get enough community activities or would you like more?

RESPONDENTS	ENOUGH	SOMETIMES	MORE
70	60%	1%	39%

84. Is (support person) nice and polite to you?

RESPONDENTS	NICE	IN-BETWEEN	NOT NICE
72	96%	1%	3%

85. Did you choose (or pick) who helps you with your community activities?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
67	33%	31%	36%

86. Show me how you feel about the people you spend time with during the day.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
91	87%	9%	4%

87. Do the people you spend time with during the day treat you okay, or do they not respect you?

RESPONDENTS	RESPECT	IN-BETWEEN	NO RESPECT
70	97%	0%	3%

88. Show me how you feel about your community activities.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
91	85%	10%	5%

89. Have you had too many different people support you during the day?

RESPONDENTS	NO	SOMETIMES	YES
65	79%	6%	15%

90. Is there something else you would rather do during the day?

RESPONDENTS	NO	SOMETIMES	YES
69	67%	4%	29%

91. Do you choose to go to your community activities, or do you have to go?

RESPONDENTS	CHOOSE	SOMETIMES	HAVE TO GO
67	67%	3%	30%

COMMUNITY ACTIVITIES- GROUP SUPPORT

92. Do you like your community activities or do you not like them?

RESPONDENTS	LIKE	SOMETIMES	NOT LIKE
7	100%	0%	0%

93. Did you choose (pick) your community activities?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
7	14%	86%	0%

94. Do you like doing those activities?

RESPONDENTS	YES	IN-BETWEEN	NO
7	100%	0%	0%

95. Do you get enough community activities or would you like more?

RESPONDENTS	ENOUGH	SOMETIMES	MORE
6	67%	0%	33%

96. Is (support person) nice and polite to you?

RESPONDENTS	NICE	IN-BETWEEN	NOT NICE
7	100%	0%	0%

97. Did you choose (or pick) who helps you with your community activities?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
4	50%	50%	0%

98. Show me how you feel about the people you spend time with during the day.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
10	80%	20%	0%

99. Do the people you spend time with during the day treat you okay, or do they not respect you?

RESPONDENTS	RESPECT	IN-BETWEEN	NO RESPECT
7	100%	0%	0%

100. Show me how you feel about your community activities.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
10	70%	30%	0%

101. Have you had too many different people support you during the day?

RESPONDENTS	NO	SOMETIMES	YES
7	100%	0%	0%

102. Is there something else you would rather do during the day?

RESPONDENTS	NO	SOMETIMES	YES
6	84%	16%	0%

103. Do you choose to go to your community activities, or do you have to go?

RESPONDENTS	CHOOSE	SOMETIMES	HAVE TO GO
5	40%	0%	60%

FRIENDS and SOCIAL SUPPORT

FRIENDS:

*104. Do you have a best friend or someone you are really close to? (Is there someone you can talk to about personal things?)

RESPONDENTS	YES	NO
153	87%	13%

*105. Do you have friends you like to talk to or do things with?

RESPONDENTS	YES NOT STAFF OR FAMILY	ALL ARE STAFF OR FAMILY	NO FRIENDS
151	74%	19%	7%

106a. Show me how ____ usually makes you feel. (Average natural friends 1-3)

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
106	89%	10%	1%

106b. Show me how ____ usually makes you feel. (Average staff or family friends 1-3)

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
58	91%	7%	2%

107. Do you have enough friends or do you wish you had more friends?

RESPONDENTS	ENOUGH	MORE
148	60%	40%

*108. Can you see your friends when you want to see them?

RESPONDENTS	YES	SOMETIMES	NO
148	88%	7%	5%

109. Who do you talk to when you need to talk to someone?

RESPONDENTS	SOMEONE	NO ONE
143	97%	3%

110. Does anyone ever ask you to help them?

RESPONDENTS	SOMEONE	NO ONE
152	70%	30%

111. On most days, are you usually happy or sad?

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
152	74%	22%	4%

112. Are you lonely or do you have plenty of friends?

RESPONDENTS	PLENTY	IN-BETWEEN	LONELY
151	73%	16%	11%

*113. Do you ever feel lonely, like you don't have anyone to talk to?

RESPONDENTS	NO	SOMETIMES	YES
142	60%	30%	10%

FAMILY:

*114. (For those with family they can name) Do you ever get to see your family?

RESPONDENTS	YES	SOMETIMES	NO
115	87%	5%	8%

*115. Can you see your (named) family when you want to?

RESPONDENTS	YES	SOMETIMES	NO
125	84%	9%	7%

116. Show me how you feel about these (named) family members.

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
149	91%	6%	3%

ACTIVITIES

What do you do for fun? Can you tell me some things you do for fun?

*117. Do you ever go shopping?

117a. (If q117=Yes) Do you go to shop as much as you want or do you want to go more?

RESPONDENTS	AS MUCH AS I WANT	WANT MORE
138	62%	38%

117b. (If q117=No) Do you ever want to go shopping?

RESPONDENTS	NO	YES
6	50%	50%

*118. Do you ever run errands or go to appointments?

118a. (If q118=Yes) Do you run errands or go to appointments as much as you want or do you want to go more?

RESPONDENTS	AS MUCH AS I WANT	WANT MORE
141	84%	16%

118b. (If q118=No) Do you ever want to go on errands/appointments?

RESPONDENTS	NO	YES
6	50%	50%

*119. Do you ever exercise or play sports?

119a. (If q119=Yes) Do you exercise/play sports as much as you want or do you want to do more?

RESPONDENTS	AS MUCH AS I WANT	WANT MORE
115	56%	44%

119b. (If q119=No) Do you ever want to exercise/play sports?

RESPONDENTS	NO	YES
34	44%	56%

*120. Do you ever go out to entertainment?

120a. (If q120=Yes) Do you go out to entertainment as much as you want or do you want more?

RESPONDENTS	AS MUCH AS I WANT	WANT MORE
105	57%	43%

120b. (If q120=No) Do you ever want to go out to entertainment?

RESPONDENTS	NO	YES
45	56%	44%

*121. Do you ever go out to eat?

121a. (If q121=Yes) Do you go out to eat as much as you want or do you want to go more?

RESPONDENTS	AS MUCH AS I WANT	WANT MORE
122	67%	33%

121b. (If q121=No) Do you ever want to go out to eat?

RESPONDENTS	NO	YES
23	43%	57%

*122. Do you ever go to church or synagogue?

122a. (If q122=Yes) Do you go to church or synagogue as much as you want or do you want to go more?

RESPONDENTS	AS MUCH AS I WANT	WANT MORE
49	61%	39%

122b. (If q122=No) Do you ever want to go to church or synagogue?

RESPONDENTS	NO	YES
94	73%	27%

*123. Do you ever go to other community meetings?

123a. (If q123=Yes) Do you go to other community meetings as much as you want or do you want to go more?

RESPONDENTS	AS MUCH AS I WANT	WANT MORE
42	65%	35%

123b. (If q123=No) Other community meetings -No: Do you ever want to go shopping?

RESPONDENTS	NO	YES
95	76%	24%

GUARDIANSHIP

124. Do you get to see or talk to your guardian when you want to? (Persons with guardianship)

RESPONDENTS	YES	SOMETIMES	NO
77	90%	6%	4%

125. Did you get to choose (pick) your guardian, or did someone else choose your guardian?

RESPONDENTS	I CHOSE	SOMEONE ELSE CHOSE
65	52%	48%

126. Show me how you feel about (guardian).

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
102	82%	15%	3%

127. Does your guardian let you make some decisions for yourself or does she/he make decisions for you?

RESPONDENTS	OWN DECISIONS	GUARDIAN DECIDES
75	69%	31%

128. Do you want to change who your guardian is?

RESPONDENTS	NO	MAYBE	YES
72	90%	2%	8%

SELF-ADVOCACY

*129. Have you ever gone to a self-advocacy meeting, conference or event?

RESPONDENTS	YES	NO
143	39%	61%

130a. (If q129=Yes) Do you want to go to a self-advocacy meeting, conference or event?

RESPONDENTS	YES	NO
41	76%	24%

130b. (If q129=No) Do you want to go to a self-advocacy meeting, conference or event?

RESPONDENTS	YES	NO
80	38%	62%

131. (If q129=Yes) Why did you go to the self-advocacy meeting, conference, or event?

RESPONDENTS	INFORMATION	SOCIAL OPPORTUNITY	PART OF ADVOCACY MOVEMENT	OTHER
37	51%	14%	14%	21%

*132. (If q129=No) Why haven't gone or been able to go?

RESPONDENTS	NO TIME	NOT INTERESTED	NO RIDE	DIDN'T KNOW ABOUT IT	OTHER
58	9%	38%	3%	40%	10%

133. Do you see yourself as being a self-advocate?

RESPONDENTS	YES	NO
143	82%	18%

134. Do you want to know more about self-advocacy?

RESPONDENTS	YES	NO
137	54%	46%

VOTING

135. Has anyone ever talked to you about voting in elections?

RESPONDENTS	YES	NO
143	52%	48%

136. Have you ever voted in an election?

RESPONDENTS	YES	NO
148	42%	58%

137a. (If have voted) Do you want to vote in an election?

RESPONDENTS	YES	NO
57	86%	14%

137b. (If have not voted) Do you want to vote in an election?

RESPONDENTS	YES	NO
83	34%	66%

SERVICE AGENCY

*138 Do you know your service coordinator/case manager?

RESPONDENTS	YES	NOT SURE	NO
169	88%	6%	6%

139. Show me how you feel about (your case manager).

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
169	90%	6%	4%

*140. Did you choose (or pick) (your case manager)?

RESPONDENTS	YES WITHOUT HELP	YES WITH HELP	NO SOMEONE ELSE CHOSE
137	31%	27%	42%

141. Do you get to see (your case manager) when you want to?

RESPONDENTS	YES	SOMETIMES	NO
138	85%	9%	6%

142. When you want to talk to (your case manager) is it hard or easy to get in touch with him/her?

RESPONDENTS	EASY	IN-BETWEEN	HARD
136	63%	19%	18%

*143. Does he/she ask you what you want?

RESPONDENTS	YES	SOMETIMES	NO
131	79%	6%	15%

*144. If you ask for something, does he/she help you get you what you need?

RESPONDENTS	YES	SOMETIMES	NO
133	91%	4%	5%

145. Have you had too many different service coordinators/case managers?

RESPONDENTS	NO	IN-BETWEEN	YES
126	76%	3%	21%

146. Show me how you feel about (your service agency).

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
173	83%	13%	4%

147. Did you have a support plan (ISA) meeting this year?

RESPONDENTS	YES	NO
128	73%	27%

148. When you have your support plan (ISA) meetings, do people listen to what you have to say?

RESPONDENTS	LISTEN	SOMETIMES	NOT LISTEN
99	94%	4%	2%

149. Are the things that are important to you in your support plan (ISA)?

RESPONDENTS	YES	SOMETIMES	NO
94	88%	4%	8%

150. Do you have a group of friends or family that you count on to help you make decisions?

RESPONDENTS	YES	SOMETIMES	NO
144	85%	2%	13%

151. Do you get the services you need?

RESPONDENTS	YES	SOMETIMES	NO
146	90%	2%	8%

*152. (Waiver or flexible funding consumers only) Do you know how much money the agency has to pay for your worker(s)/services?

RESPONDENTS	YES	IN-BETWEEN	NO
110	15%	3%	82%

153. (Waiver or flexible funding consumers only) When you have your ISA meeting, does your case manager tell you how much money is in your waiver/budget?

RESPONDENTS	YES	IN-BETWEEN	NO
98	53%	4%	43%

154. Do people at (your agency) listen to you or not listen to you?

RESPONDENTS	LISTEN	SOMETIMES	NOT LISTEN
145	89%	6%	5%

155. Are you having trouble getting the help you need from people at (your agency) or are you getting the help you need?

RESPONDENTS	GETTING HELP	SOMETIMES	TROUBLE
146	87%	5%	8%

156. Who would you ask to help you change services or supports you do not like?

RESPONDENTS	NAMED	SOMEONE, BUT DID NOT NAME	NOBODY NAMED
119	86%	7%	7%

*157. Do people help you do or learn new things?

RESPONDENTS	YES	SOMETIMES	NO
150	80%	7%	13%

*158. Do you want (more) help to do or learn new things?

RESPONDENTS	YES	SOMETIMES	NO
101	32%	34%	34%

159. Show me how you feel about the help you get from (your agency).

RESPONDENTS	HAPPY	IN-BETWEEN	SAD
173	84%	9%	7%

160. Have you ever been told about (your agency's) complaint process or are you not aware of (your agency's) complaint process?

RESPONDENTS	TOLD	NOT AWARE
144	37%	63%

161. Have you ever made a formal written complaint to someone at your agency?

RESPONDENTS	NO	YES
143	93%	7%

162. Have you been told about (your agency's) appeal process or are you not aware of (your agency's) appeal process?

RESPONDENTS	TOLD	NOT AWARE
140	33%	67%

SELF-DETERMINATION

163. Do you need to have more control over your life or do you think you have enough control?

RESPONDENTS	ENOUGH	IN-BETWEEN	MORE
144	82%	4%	14%

164. Are there choices you wish you could make that you don't make now?

RESPONDENTS	NO	YES NOT NAMED	YES NAMED
138	64%	16%	20%

165. Do you need to know more about how to interview and hire your support staff?

RESPONDENTS	NO	YES
135	59%	41%

SECTION 3

PARTICIPANT PROFILE 2004

WHO PARTICIPATED

This Section is intended to give an overall picture of the adults receiving developmental services statewide. It reports findings from the 2004 Demographics Survey, including new communication effectiveness and support information as follows:

- **Basic Demographics (Tables 3.1-3.3)** covers Personal Characteristics, Legal Factors, and Family Involvement.
- **Communication Capability (Tables 3.4-3.6)** covers Means of Communication, Communication Effectiveness, and Communication Supports.
- **Medical/Health Issues (Tables 3.7-3.9)** covers Developmental Disability, Other Challenges, and Healthcare and Lifestyle.
- **Residential Information (Tables 3.10-3.12)** covers Type of Residence, Residential Characteristics, and Guardianship by Residential Type.
- **Services (Tables 3.13-3.14)** covers Type of Services Received and Self-Management of Services.

Each of the tables in these reporting categories includes percentages for those interviewed, those not interviewed, and all participants. For ease of reading, the definition of the data reported (left hand column) and the data for all participants served statewide (right hand column) are shown in bold.

BASIC DEMOGRAPHICS

Table 3.1 - Personal Characteristics

Characteristic	Interviewed (n=188)	Not Interviewed (n=185)	All Participants (n=373)
Age			
Average Age	41	40	41
Minimum	19	18	18
Maximum	83	88	88
Gender			
Male	60%	62%	61%
Female	40%	38%	39%
Marital Status			
Single	90%	92%	90%
Married/Civil Union	4%	5%	5%
Married/Civil Union in Past	6%	3%	5%
Race			
White	97%	81%	90%
American Indian/Eskimo/Aleut	1%	2%	1%
Asian	0%	1%	0%
Black	1%	0%	0%
Unknown	1%	16%	9%
Primary Language			
English	100%	99%	99%
Other	0%	1%	1%

Table 3.2 - Legal Factors

	Interviewed (n=188)	Not Interviewed (n=185)	All Participants (n=373)
Guardianship			
No Guardian	37%	29%	33%
Private Guardian	43%	47%	45%
Public Guardian	20%	24%	22%
Unknown	<0.5%	0%	<0.5%
Payee			
No Payee	24%	33%	29%
Payee	72%	63%	67%
Unknown	4%	4%	4%
Court Restrictions			
No	89%	80%	85%
Yes	10%	16%	13%
Unknown	1%	4%	2%

Table 3.3 - Family Involvement in People's Lives

	Interviewed (n=188)	Not Interviewed (n=185)	All Participants (n=373)
Family Involved			
Yes	89%	81%	85%
No	10%	16%	13%
Unknown	1%	3%	2%
Why Family not Involved	(n=22)	(n=29)	(n=51)
Family gone/not alive/ whereabouts unknown	23%	28%	25%
Family choice	45%	52%	49%
Court restriction	9%	3%	6%
Other	23%	3%	12%
Unknown	0%	14%	8%

COMMUNICATION CAPABILITY

Table 3.4 – Means of Communication

	Interviewed (n=188)	Not Interviewed (n=185)	All Participants (n=373)
Adequate Reliable Speech			
Yes	79%	53%	66%
No	21%	45%	33%
Unknown	0%	2%	1%
Primary Means of Communication			
Spoken - Understood by familiar listener	92%	68%	80%
Gesture/body language	5%	26%	15%
Sign language/finger spelling	1%	2%	2%
Communication aid/device	1%	0%	1%
Other	1%	3%	1%
Unknown	0%	1%	1%

Table 3.5 – Communication Effectiveness for People with Inadequate Speech

	Interviewed (n=39)	Not Interviewed (n=83)	All Participants (n=122)
Communicate with familiar people			
Yes	100%	93%	95%
No	0%	7%	5%
Unknown	0%	0%	0%
Communicate with unfamiliar people			
Yes	77%	44%	54%
No	20%	48%	39%
Unknown	3%	8%	7%
Communicate beyond basic needs			
Yes	67%	44%	51%
No	31%	43%	39%
Unknown	2%	13%	10%
Communication effectiveness in last year			
More effective	31%	17%	21%
As effective	62%	70%	68%
Less effective	0%	0%	0%
Fair assessment not possible	0%	5%	3%
Unknown	7%	8%	8%

Table 3.6 – Communication Supports for People with Inadequate Speech

	Interviewed (n=39)	Not Interviewed (n=83)	All Participants (n=122)
Communication addressed in ISA			
Yes	54%	44%	47%
No	46%	55%	52%
Unknown	0%	1%	1%
Communication Supports in Place			
Consistent comm. partners	97%	89%	92%
Team support	100%	88%	92%
Access to comm. aids/devices	62%	39%	46%
Training support for support wkers	72%	73%	73%
Expert consultation/support	64%	55%	58%

MEDICAL/HEALTH ISSUES

Table 3.7 - Developmental Disability

Disability Label	Interviewed (n=188)	Not Interviewed (n=185)	All Participants (n=373)
Mild MR	72%	42%	57%
Moderate MR	21%	30%	26%
Severe MR	4%	18%	11%
Profound MR	0%	6%	3%
Unspecified MR	2%	2%	2%
Unknown/Not reported	1%	2%	1%

Table 3.8 - Other Challenges

Challenge	Interviewed (n=188)	Not Interviewed (n=185)	All Participants (n=373)
Mental Illness	24%	23%	24%
Autism	5%	7%	6%
Cerebral Palsy	11%	8%	9%
Brain Injury	1%	5%	3%
Chemical dependence	2%	1%	1%
Physical disability	11%	15%	13%
Hearing	14%	6%	10%
Vision	19%	24%	21%
Seizures	18%	24%	21%
Communication disorder	4%	14%	9%
Alzheimers disease	1%	1%	1%
Down Syndrome	9%	9%	9%
Non-Ambulatory	14%	18%	16%
Other	3%	12%	8%

Table 3.9 - Healthcare and Lifestyle

	Interviewed (n=188)	Not Interviewed (n=185)	All Participants (n=373)
Last Physical Examination			
In the past year	81%	76%	78%
Over 1 year ago	11%	9%	10%
Unknown	8%	15%	12%
Last Dental Examination			
In the past six months	57%	52%	55%
Over 6 months ago	22%	18%	20%
Unknown	21%	30%	25%
Medical Care Required			
Less than once/month	74%	75%	74%
At least once/month	11%	7%	9%
At least once/week or more	4%	5%	5%
Unknown	11%	13%	12%
Seizure Frequency			
No seizures	84%	73%	79%
Less than once/month	9%	12%	11%
At least once/month	4%	4%	4%
At least once/week or more	2%	5%	3%
Unknown	1%	6%	3%
Vision			
Sees well (with/without correction)	86%	77%	82%
Vision problems limit activities	7%	10%	9%
Limited or no vision (legally blind)	4%	8%	6%
Unknown	3%	5%	4%
Level of Mobility			
Walks or uses wheelchair	96%	87%	91%
Non-ambulatory needs assistance	3%	12%	8%
Unknown	1%	1%	1%
Physically Active			
Very physically active	17%	16%	16%
Moderately physically active	66%	60%	63%
Physically inactive	15%	22%	18%
Unknown	2%	2%	2%
Weight concerns			
No weight concerns	62%	70%	66%
Overweight	31%	20%	25%
Underweight	3%	5%	4%
Unknown	4%	5%	4%
Smoke/chew tobacco			
No	84%	86%	85%
Yes	13%	11%	12%
Unknown	3%	3%	3%

RESIDENTIAL INFORMATION

Table 3.10 - Type of Residence

Residential Type	Interviewed (n=188)	Not Interviewed (n=185)	All Participants (n=373)
Provider Home	35%	39%	37%
Family Home	26%	31%	29%
Person's Own Home	28%	22%	25%
Group Living	8%	5%	6%
Staffed Living	1%	1%	1%
Residential Care Home	1%	0%	0.5%
Nursing facility	1%	1%	1%
Other	0%	1%	0.5%

Table 3.11 – Guardianship by Residential Type

Residential Type	No Guardian (n=70)	Private Guardian (n=80)	Public Guardian (n=37)	Total (n=187) *
Provider Home	11%	41%	68%	35%
Family Home	19%	44%	3%	27%
Person's Own Home	63%	3%	16%	28%
Group Living	3%	11%	11%	8%
Staffed Living	1%	1%	0%	1%
Residential Care Home	1%	0%	3%	1%
Nursing facility	1%	0%	0%	1%

* Guardianship for one consumer completing the survey was not reported

Table 3.12 - Residence Characteristics

Residential Characteristic	Interviewed (n=188)	Not Interviewed (n=185)	All Participants (n=373)
Location			
Remote	48%	46%	47%
Walking distance to town	38%	31%	35%
Centrally located in town	14%	21%	17%
Unknown	0%	1%	1%
Ownership/Lease of Home			
Family/guardian	29%	30%	30%
Individual/family person lives with	37%	41%	39%
Provider agency/affiliate	13%	10%	11%
Person rents home	15%	11%	13%
Person owns home	4%	4%	4%
Unknown	1%	1%	1%
Other	1%	3%	2%
Amount of Residential Support			
No on-site support (Indep./family)	32%	32%	32%
24 hour on-site	46%	51%	48%
Daily on-site	8%	5%	7%
Less frequent than daily	8%	7%	8%
As needed	4%	3%	3%
Unknown	2%	2%	2%
Household Composition			
Non-related individuals	41%	48%	45%
Biological/adoptive parents	23%	24%	24%
Lives alone	15%	12%	13%
Spouse/Civil Union	4%	4%	4%
Minor children only	1%	1%	1%
Other relatives	10%	8%	9%
Other	6%	3%	4%
Time in current home/with current provider			
More than 5 years	56%	53%	54%
3-5 years	16%	17%	16%
1-2 years	16%	16%	16%
Less than 1 year	11%	10%	11%
Unknown	1%	4%	3%

SERVICES

Table 3.13 - Types of Services Received

Service Type	Interviewed (n=188)	Not Interviewed (n=185)	All Participants (n=373)
Residential Supports*	44%	45%	45%
Service Coordination	92%	90%	91%
Employment - Individual supported	52%	33%	42%
Employment - Enclave/workcrew	2%	1%	1%
Community Support	55%	60%	57%
Clinical Services	40%	44%	42%
Transportation	49%	39%	44%
Family Supports - Respite/FFF	42%	48%	45%
Other Supports	10%	5%	8%

* In Provider Home, Group Living, or Staffed Living

Table 3.14 - Self-Management of Services

	Interviewed (n=188)	Not Interviewed (n=185)	All Participants (n=373)
Management of Services			
Self or Shared with Agency	10%	9%	9%
Family or Shared with Agency	8%	13%	11%
Agency Managed	79%	73%	76%
Unknown	3%	5%	4%
Individually Negotiated Budget			
Yes	73%	72%	73%
No	21%	21%	21%
Unknown	6%	7%	6%
Individual Support Agreement (ISA)			
Yes	91%	87%	89%
No	8%	11%	10%
Unknown	1%	2%	1%
Fiscal Intermediary (ISO/private payroll)			
Yes	30%	30%	30%
No	63%	63%	63%
Unknown	7%	7%	7%
Independent Support Broker (ISB)			
Yes	2%	4%	3%
No	94%	88%	91%
Unknown	4%	8%	6%

SECTION 4

METHODOLOGY

HOW THIS SURVEY IS CONDUCTED

Since the inception of the statewide consumer surveys in 1995, the State Division of Disability and Aging Services has taken steps to provide a forum for people receiving developmental services to express their own point of view while eliminating possible bias or influence. For this reason, the surveys have always been administered by an independently contracted team. Originally, this work was contracted to a team from the University of Vermont. Since 2003, survey administration and data entry has been coordinated by Rosemary Drabing, M.S.W., and Janet Bramley Ph.D. has been responsible for survey analysis and reporting. Survey responses remain confidential and personally identifying data are removed before the survey responses are analyzed.

The Vermont Consumer Survey is conducted statewide over a 3 year period, 2004 marking the start of the third such 3-year cycle. Within each year, a sample of adults receiving developmental services is surveyed. This Section describes the methodology used to obtain and analyze information for the 2004-2006 Vermont Consumer Survey. The information in this Section covers:

- **Participant Selection:** How people are chosen to take part in the survey to obtain a fair representation of the adults receiving developmental services in the state of Vermont and their views in a variety of life satisfaction domains.
- **The Survey Instruments:** A brief description of the questionnaires used to obtain demographic and satisfaction information.
- **Survey Administration:** A description of how demographic information is collected and the participant interview procedure.
- **Survey Analysis and Reporting:** A description of the analytical procedures used to derive the findings presented in this report.

PARTICIPANT SELECTION

The selection of adults to participate in the consumer survey is designed to be representative both within each agency and to be representative of the statewide population receiving developmental services in each year. Five or six agencies are chosen each year. In the summer of 2004, the independently contracted survey interviewers visited the same six agencies as were surveyed in 2001; the agencies visited in 2005 will be the same as those in 2002 and likewise, those visited in 2006 will be the same as those in 2003.

The selection of participants is the first stage of the survey process each year. During springtime, a random sample based on the size of agency and regional representation is drawn from the list of people currently served by the agency. These are the potential survey participants for that summer. The percentage of individuals served by each agency who are invited to participate is shown in Table 4.1.

Table 4.1 –Sample Size by Agency as a Percentage of Adults Served

Agency	2004	2005	2006
Champlain Vocational Services	100%		
Community Access Program (RMHS-CAP)			50%
Community Associates (CSAC-CA)	50%		
Community Developmental Services (WCMH-CDS)			50%
Health Care and Rehabilitation Services of Southeastern Vermont (HCRS)		50%	
Howard Center for Human Services (HCHS)	33%	33%	33%
Lamoille County Mental Health Services (LCMH)			100%
Lincoln Street Incorporated (LSI)			100%
Northeast Kingdom Human Services (NKHS)	50%		
Northwestern Counseling and Support Services (NCSS)		50%	
Specialized Community Care (SCC)	100%		
Sterling Area Services (SAS)		100%	
Upper Valley Services (UVS)		50%	
United Counseling Service (UCS)	50%		

The Demographic Survey is used to collect information about all participants. The agency then makes a determination as to which people can also participate in satisfaction interviews. While it is recognized that not all participants are able or willing to be interviewed, the aim is to interview 60% of participants.

THE SURVEY INSTRUMENTS

Two survey instruments are used: the Demographic Survey and the Consumer Interview. These instruments were developed and extensively field-tested for reliability by Susan Culbert, Ph.D., and Sara Burchard, Ph.D. during the early 1990s. The format and questions had been reviewed and approved by a variety of stakeholders including self-advocates, family members, service providers, and representatives from the State Division of Developmental Services, prior to the survey instruments' first statewide use in 1995.

Since the first 3-year cycle of surveys, a number of questions have been changed or added to the original survey instruments. For the second cycle of surveys, questions addressing knowledge of services and self-determination were added to the Consumer Interview in response to consumer advocacy requests. It was at this time also that the State started submitting survey data to the National Core Indicators (NCI) project. This project currently includes 21 states and provides an annual comparative 'report card' on services for adults receiving developmental services. For the current cycle of surveys, the Demographic Survey, in particular, has been further enhanced. This has been partly to include more questions on communication capabilities and services to inform the current communication

initiative, and partly, to align more closely with questions with the National Core Indicators (NCI) project to enable more cross state comparisons. Revisions to the current Consumer Interview have been primarily clarifications and matching up to the NCI Survey wording rather than additional questions.

The Demographic Survey is filled out by case managers at the participating agencies prior to the interviews with the people receiving services. The information gathered can be used in the first instance by the interviewers to inform and facilitate the interview process. It has also proved over the last decade to be a valuable resource for obtaining a comprehensive ongoing picture of the population of adults receiving developmental services here in Vermont. The Demographic Survey consists of sections covering general demographics, communication capabilities and services, medical and health information, behavioral challenges, residential characteristics, services and self management and self determination. The information from the Demographic Survey is reported in section 3 of this Report.

The structured Consumer Interview consists of 165 questions designed to measure how satisfied people receiving developmental services are in a variety of life domains: how they feel about their residential living, work and/or community activities, community services, and activities. It also obtains information on other valued outcomes, such as social support, neighbors, leisure activities, degree of independence, opportunities for growth and change, self-advocacy, and self-determination. Each question on the survey has a high value of 2 (positive response) and a low of 0 (negative response). The values for 'Not Applicable', 'Refused' or 'Unclear/unknown' are excluded from the analysis. On average, the direct interviews will take between 30 and 35 minutes to complete. For people who have difficulty with verbal communication, there is an abbreviated version of the Consumer Interview covering the same satisfaction domains, in which picture cards ('Happy', 'In-between' and 'Sad') are used for respondents to indicate their answers. The information from the Consumer Interview is reported in section 2 of this Report.

Copies of the survey instruments may be requested from the Division of Disability and Aging Services.

SURVEY ADMINISTRATION

Rosemary Drabing, an independent contractor with extensive experience with the Vermont developmental service system, took over project coordination in 2003, the last year of the previous cycle of surveys. In each year, field interviewers are hired and trained to complete the consumer interviews. Typically, interviewers have included graduate students, teaching and human services professionals, and consumers of developmental services.

Once the participant pool has been selected (see page 49), the project coordinator meets with service coordinators at the participating agencies and distributes copies of the Demographic Survey to be filled out before the interviews. It is at this time that a determination will be made by the agencies as to which of the randomly selected adults can also participate in direct interviews. Arrangements are then made for the direct interviews to take place.

Generally, the participants are interviewed alone at the agency offices to allow them to express their opinions freely. However, accommodations are made as necessary, for example, if the individual wants someone present or an interpreter is needed or the individual cannot get to the office. The interview questions are read by the interviewer and the answers are recorded on the questionnaire forms. Not all survey questions are applicable for every person, and not all people will answer all of the questions in their interviews. On a few occasions, it will be clear that the person has difficulty with the questions and cannot complete the interview. Should this happen, the interviewer may switch to the picture version of the survey, or the interview will be respectfully terminated and the responses will not be included in the survey analysis.

SURVEY ANALYSIS

All data entry and analysis is performed using standard SPSS TM statistical software (Version 10.0.7) and the charts appearing in these reports are generated using Microsoft ExcelTM to format output from the SPSS analysis.

On completion of the interview sessions, the completed Demographic Survey and Consumer Interview questionnaires are returned to the project coordinator for entry into an SPSS database. Each participant is identified by agency and a survey number; no personally identifying information is entered into this database. The database is then submitted to the Evaluator for analysis. Janet Bramley, the Evaluator for this project has been connected with the Consumer Survey Project first as an interviewer and later as an evaluator since 1995.

The analysis of responses to the two survey instruments involves two stages. In the first instance, simple descriptive cross-tabulation statistics are used to generate data for the tables in Sections 2 (Interview responses) and Section 3 (Demographic Survey findings) of this Report.

The second stage involves, grouping responses to the Consumer Survey into life satisfaction domains. Table 4.2 below indicates which questions were used for each of these domains. The valid responses to these questions are a high value of 2 (positive response) through a low value of 0 (negative response). The values for 'Not Applicable', 'Refused' or 'Unclear/unknown' are excluded from the analysis. For each domain the mean of the valid responses to the indicated questions is divided by 2 and multiplied by 100 to give a percentage satisfaction rate. These percentage rates are then further analyzed using Analysis of Variance (ANOVA) procedures to determine whether there were significant differences between different groups of people (Domain Satisfaction, page 6, and pages 12-13)

Table 4.2 – Survey Questions Used for Generating Domain Satisfaction Scores*

Domain	Survey Questions Used for Domain Scores
Residential	1, 4, 5, mean9, mean10, mean11, 14, 15, 16, 18, 19, 20 22, 23, 25, 27, 43, 45, 46, 47, 48, 49, 52, 53, 55, 56
Residential Autonomy	2, 3, 6, 7, 8, 12, 13, 17, 21, 24, 26, 28, 29, 30, 31, 32, 33, 34, 35, 39, 40, 41, 42, 44, 50, 51
Neighborhood	57, 58, 59, 60, 61
Work	64, 65, 66, 67, 68, 69, 70, 71, 72, 73, 74, 76
Community Supports	80, 81, 82, 83, 84, 85, 86, 87, 88, 92, 93, 94, 95, 96, 97, 98, 99, 100
Social Support	104, 105, mean106, 107, 108, 109, 110, 111, 112, 113, 114, 115, 116
Activities	117a, 118a, 119a, 120a, 121a, 122a, 123a, 117b, 118b, 119b, 120b, 121b, 122b, 123b
Guardian	124, 125, 126, 127
Community Services	139, 140, 141, 142, 144, 145, 146, 147, 148, 149, 150, 154, 155, 156, 157, 159
Self Determination/Rights	129, 136, 152, 153, 160, 162, 163, 164, 165

*Note: The Self Determination/Rights scale is new and based on questions added to the survey in accordance with the National Core Indicators and in response to feedback from advocates. The Health Satisfaction from previous surveys is no longer examined as those questions were removed from the survey. However, full demographic information on Healthcare and Lifestyle scale is shown in Table 3.9.